

Principles of care

Delivering care

Children and young people with spasticity should have access to a network of care that uses agreed care pathways supported by effective communication and integrated team working.

The network of care should provide access to a team of healthcare professionals experienced in the care of children and young people with spasticity. The network team should provide local expertise in paediatrics, nursing, physiotherapy and occupational therapy. Access to other expertise, including orthotics, orthopaedic surgery and/or neurosurgery and paediatric neurology, may be provided locally or regionally.

If a child or young person receives treatment for spasticity from healthcare professionals outside the network team, this should be planned and undertaken in discussion with the network team to ensure integrated care and effective subsequent management.

Management programmes

Following diagnosis, ensure that all children and young people with spasticity are referred without delay to an appropriate member of the network team.

Offer a management programme that is:

- developed and implemented in partnership with the child or young person and their parents or carers
- individualised
- goal focused.

When formulating a management programme take into account its possible impact on the individual child or young person and their family.

Carefully assess the impact of spasticity in children and young people with cognitive impairments:

- be aware that the possible benefit of treatments may be more difficult to assess in a child or young person with limited communication
- ensure that the child or young person has access to all appropriate services.

Identify and agree with children and young people and their parents or carers assessments and goals that:

- are age and developmentally appropriate
- focus on the following domains of the [World Health Organization's International Classification of Functioning, Disability and Health \(children and youth version\)](#):
 - body function and structure
 - activity and participation.

Record the child or young person's individualised goals and share these goals with healthcare professionals in the network team and, where appropriate, other people involved in their care.

Help children and young people and their parents or carers to be partners in developing and implementing the management programme by offering:

- relevant, and age and developmentally appropriate, information and educational materials
- regular opportunities for discussion **and**
- advice on their developmental potential and how different treatment options may affect this.

Monitoring

Monitor the child or young person's condition for:

- the response to treatments
- worsening of spasticity
- developing secondary consequences of spasticity, for example pain or contractures
- the need to change their individualised goals.

The network of care should have a pathway for monitoring children and young people at increased risk of hip displacement.

Recognise the following clinical findings as possible indicators of hip displacement (hip migration greater than 30%):

- pain arising from the hip
- clinically important leg length difference
- deterioration in hip abduction or range of hip movement
- increasing hip muscle tone
- deterioration in sitting or standing
- increasing difficulty with perineal care or hygiene.

Offer a hip X-ray to assess for hip displacement:

- if there are clinical concerns about possible hip displacement
- at 24 months in children with bilateral cerebral palsy.

Consider repeating the hip X-ray annually in children or young people who are at Gross Motor Function Classification System (GMFCS) level III, IV or V.

Consider repeating the hip X-ray after 6 months in children and young people where the initial hip migration is greater than 30%, and then consider repeating the hip X-ray every 6 months after this if the hip migration is increasing by more than 10 percentage points per year.

Supporting the child or young person and their parents or carers

Offer contact details of patient organisations that can provide support, befriending, counselling, information and advocacy.

Ensure that children and young people have timely access to equipment necessary for their management programme (for example, postural management equipment such as sleeping, sitting or standing systems).

The network team should have a central role in transition to prepare young people and their parents or carers for the young person's transfer to adult services.